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## Caregiver Empowerment: How occupational therapy can make a difference in the lives of family members in sub-acute rehabilitation

### Degree Type

Capstone (Entry-Level OTD)

### Degree Name

Doctorate of Occupational Therapy (OTD)

### Subject Categories

Occupational Therapy



# Caregiver Empowerment

**How occupational therapy can make a difference in the lives of family members in sub-acute rehabilitation.**

## Author Biography

Max Holden is currently earning a doctorate degree in occupational therapy from Pacific University, OR. Max intends to focus his career on serving older adults with disabilities within sub-acute rehabilitation settings with a special interest in supporting and empowering family caregivers.

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As a student occupational therapist I completed my Level IIA Fieldwork rotation within a skilled nursing facility. I had an opportunity to work with a middle-aged gentleman admitted with multiple fractures following a significant motor cycle accident. With assurance, I traversed the building with a steady gait and singularity of purpose. I approached his room, glanced left through the door, saw five or six family members engaged in a heated discussion, and without losing stride I looked straight ahead and kept right on walking.

With comical reflection, I am surprised at my initial intimidation of working with family members. I discovered that I was underprepared to dive into this enigmatic subculture of healthcare. This prompted a determination to build my skills and confidence in this critical area.

I had an additional opportunity to work with a gentleman in his 60's who experienced a stroke. The patient's wife visited to observe a treatment session. With a tense voice and a bewildered expression she exclaimed, "He's going to get better, right? Just last week he was up at the lake giving his grandchildren a ride in his boat. He can't come home like this, I can't take care of him!" From this experience, I recognize how sincerely I want to make a difference in the lives of family members who care for older adults with disabilities. Therefore, my doctoral experiential capstone project focuses on this very important topic, and I aim to provide other occupational therapists with simple strategies that will facilitate better outcomes for both client's and family members in sub-acute rehab.

## **Method**

The Caregiver Empowerment initiative utilizes the Model of Human Occupation (MOHO) as a guiding model of practice for supporting, understanding, and interacting with family members (Kielhofner, 1980). Through MOHO, the OT practitioner considers:

- The family member's role identity, values, interests, and motivation for occupation.

- How the family member organizes daily activities into patterns and routines within environmental contexts.
- The physical, mental, and emotional capacity of the family member (Kielhofner, 2009).

The capstone project comprises a phenomenological research study involving quantitative and qualitative data collection and analysis followed by the development of clinical practice guidelines. The student occupational therapist developed the Family Caregiver Questionnaire (Appendix A) to identify caregiver needs. Additionally, the Caregiver Self-Assessment Questionnaire was administered in order to provide a standardized measure for the caregiver experience ("Caregiver Self-Assessment Questionnaire," 2016).

Participants were selected based off the following criteria:

- Any caregiver of a patient at least 65 years or older, willing to participate.
- Any caregiver who anticipates providing supervision or assistance to their loved one.
- Caregivers at risk for increased stress and/or health decline.

Data was collected and analyzed by the student occupational therapist. A follow-up questionnaire (Appendix B) was developed to determine if positive outcomes were reached. Due to time limitations, follow-up services were administered through informal interview within the facility prior to discharge.

## **Understanding caregivers**

Gibson, Kelly, and Kaplin (2012) define a caregiver as any relative, friend, or neighbor who has an established relationship with a disabled person to whom they provide any level of assistance. It is estimated that one out of every five households in the United States is affected by caregiving responsibilities (National Alliance for Caregiving, 2004). Coughlin (2010) reports that there are an

estimated 52 million caregivers in the US. Caregivers provide an estimated 90% of all long-term healthcare in the US (Institute of Medicine, 2008). This represents upwards of 450 billion dollars annually of unpaid healthcare services (Feinberg, Reinhard, Houser, & Choula, 2011).

Eleven participants fit the selection criteria during the study and seven participants returned the questionnaires. Participants provided the following information:

The Family Caregiver Questionnaire reveals:

- One-hundred percent of participants report that both social engagement and leisure are most impacted by caregiver responsibilities.
- The most challenging aspects of being a caregiver are imbalance in daily routines, patience, and worrying about the well-being of their loved one.
- An average score of 7.25 out of 10 regarding the level of dependency they perceive their loved one has on them (10 being total dependency).
- An average score of 7 out of 10 regarding how prepared they feel to be a caregiver (10 being 100% prepared).

The Caregiver Self-Assessment Questionnaire (2016) reveals:

- Depending on the week, 42% - 57% report they don't feel comfortable leaving their family member alone.
- Depending on the week, 42% - 71% report feeling overwhelmed.
- 42% report loneliness.
- 100% report a loss in privacy/personal time.
- 57% report sleep disturbances.
- 57% report strain between work and family responsibilities.

- 50% are dissatisfied with support from family.
- Participants report an average score of 6.2 out of 10 regarding stress (10 being very high stress.)
- 71.4% of participants qualify for high degree of distress.
- 66% of participants experienced a decline in health over previous year.
- According to scoring guidelines, 85.7% of participants exhibit at least one factor that recommends they schedule an appointment with their doctor, seek relief from caregiving, and/or join a support group.

### **Barriers to meeting caregiver needs**

This topic is quickly becoming recognized as a public health issue in need of alteration (O'Shaughnessy, 2013). However, many barriers are outside the therapists control and often hinder the services that can be provided. Some of these obstacles include:

- **Reimbursement:** Third-party payers only reimburse caregiver training services when they are carried out in the immediate presence of the patient (Levine et al., 2010; O'Sullivan, 2015).
- **Bundled Payment:** Bundled payment consists of four models of care that link organizations into payment arrangements connecting financial and performance accountability for multiple services received during an episode of care rather than reimbursing for individual services ("Bundled Payments", 2016). Within certain contexts, this may limit the amount of time available to work with clients and their family.
- **Limited Time:** Scheduling conflicts, high productivity standards, insufficient time, and limited resources create a barrier to meeting with and addressing the needs of family members (O'Sullivan, 2015).

- **Health Literacy:** Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decision (“Health Literacy Interventions”, 2014).
- **Communication:** Poor communication leads to misunderstanding, lack of rapport, decreased feedback, and lack of trust (Levine et al., 2010).
- **Caregiver Disability:** Family members may have their own disability or illness, which limits their capacity for the caregiver role.
- **Intrusiveness:** Family members may exhibit negative behaviors and attitudes that become counterproductive to service delivery (O’Sullivan, 2015).

## **Guidelines for practice**

### 1. Cultivate rapport/occupational profile

Gibson et al. (2012) report that family caregivers often feel unrecognized in healthcare settings. This trend can be remediated by taking a few intentional moments during treatment to introduce ourselves to family members, educate them on the role of occupational therapy, and ask them meaningful questions to begin the process of understanding who they are. This study reveals the power of explicitly stating to caregivers that they have great value to us and we recognize the challenges they face. It is beneficial to emphasize that we are here to support and empower them.

### 2. Administer questionnaire/assessment to identify caregiver challenges, values, and needs

Collins and Swartz (2011) identify that family member’s feel valued when healthcare providers attend to their unique needs while showing interest in their well-being. Questionnaires and assessments allow for maximal feedback in minimal time. Questionnaires can be developed independently to suit the needs of each setting as demonstrated in this study (Appendix A). Other



helpful assessment tools include the Caregiver Self-Assessment Questionnaire (2016), and the Life Balance Inventory (Matuska, 2012a, 2012b).

3. Establish plan of care and develop goals in collaboration with the client and caregiver

The OT practitioner develops a caregiver training and education plan focused on enhancing caregiver knowledge, skills, and access to community resources. This process aims to support and prepare the entire family for the client's transition to the least restrictive environment (Feinberg & Houser, 2012). This step empowers the client and the family member to make collaborative decisions on how they want to live their lives (Pickens & Long, 2016).

4. Implement the plan of care

According to the National Alliance for Caregiving and AARP (2009), 75% of caregivers report they need more training and only 20% of caregivers report receiving formal training within healthcare settings. Caregiver training interventions emphasize evidence-based practice and promote client-centeredness (Gitlin, 2007). This requires ongoing research on the part of the OT practitioner to understand and apply best-practice. In order to maximize caregiver potential, it is important that family members be present during therapy sessions as often as possible. This may require scheduling appointments with family members to ensure attendance.

5. Follow-up/Outcome monitoring

Outcome monitoring highlights if caregiver support services were successful and provides ongoing data to determine what is working well and what needs improvement in service delivery. This can be accomplished by administering the same questionnaires/assessments that were implemented at the beginning of treatment in order to compare results or a separate follow up questionnaire (Appendix

B) can be implemented to monitor outcomes. When possible, it is beneficial to get measurements based off a Likert scale to document changes in caregiver preparedness and perceived levels of stress.

### **Case study – Putting it into practice**

Mrs. D, 68, experienced a right side stroke resulting in acute onset of disability. The student occupational therapist stated to Mr. D, 71, that he had great value, we recognize his challenges, and desire to ensure his needs are met during his wife's treatment. The student asked Mr. D if he would be willing to fill out a questionnaire so that we could better support him as a caregiver. Mr. D expressed his appreciation and stated, "Honestly, I'm scared as hell. I don't know how I'm going to take care of her. I don't know what this means for our life. I don't even know if she'll be able to come home."

Mr. D felt his wife was 80% dependent on him and he felt 40% prepared to care for her. Leisure and social engagement were his most impacted areas of daily life and maintaining balance was the most challenging part of being a caregiver. His priorities for treatment were for education on upper extremity management and training for safe transfers. The student adjusted the plan of care to highlight these preferences. Mr. and Mrs. D were able to demonstrate multiple safe transfers together at the time of discharge. Mr. D demonstrated increased confidence and remained highly involved in his wife's care after discharge.

### **Conclusion**

The Occupational Therapy Practice Framework (American Occupational Therapy Association, 2014) emphasizes that the achievement of health, well-being, and participation in life is dependent upon one's engagement in meaningful occupations. This study reveals that family members are often deprived of meaningful occupational engagement resulting in diminished health, well-being, and quality of life. McMillan (2005) suggests that some ways to alleviate these trends is by having a dependable

support system, increasing education on health conditions and care, enhancing communication, and promoting continuous engagement in satisfying occupations. Occupational therapists are uniquely qualified to address these areas with family members in sub-acute rehabilitation settings. It is unrealistic to believe we can solve all the challenges that family members face, but what will happen if we do nothing? If we are going to improve outcomes for our client's we must also work to improve outcomes for their family members.

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